

# **Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure**

## **Elements of ILHIE Patient Consent Management Policy**

### **1. Collection of patient “opt-out” at provider point of care**

Preference: The provider at the point of care is responsible for providing its patient with the opportunity to opt-out, including the distribution, collection and processing of opt-out forms.

#### **a. Frequency of collection**

Preference: Once per provider. See, e.g., State of Illinois Health Information Exchange Authority Data and Security Committee, Report of Preliminary Findings, p. 8, n. 17, September 19, 2012:

*“A covered entity may rely upon a prior provision of meaningful disclosure to a subject by the covered entity or by its affiliated member of an integrated delivery network, which is documented in the subject’s medical record, ... and such covered entity will not be required to provide meaningful disclosure anew[.]”*

#### **b. Duration**

Preference: A patient’s consent preference is perpetual until revoked.

#### **c. Documentation**

Preference: Provider will distribute, collect and maintain documentation of a patient’s opt-out preference, including any written consents as may be required for “specially protected” patient health information, in accordance with the provider’s own policies for the collection and maintenance of patient opt-out preferences. It is anticipated that the ILHIE Authority, through its Patient Choice and Meaningful Disclosure Work Group, will facilitate the creation of template forms for distribution and use by providers in documenting patient opt-out preferences.

#### **d. Transmission to ILHIE**

Preference: An ILHIE participant will send an electronic message (IHE standard) notifying the ILHIE of a patient’s decision to opt-out, triggering an “electronic flag” for that patient in the ILHIE’s Master Patient Index (MPI). If the ILHIE participant’s system is unable to send an electronic message in the prescribed IHE standard, the provider will have access to a secure website that will enable the entry of a patient’s opt-out decision into the ILHIE’s MPI.

**e. Reconciliation**

Preference: The last in time (i.e., the most current) consent preference on record with the ILHIE will govern all disclosure of information by the ILHIE for any particular patient.

**f. Revocation**

Preference: A patient may elect to revoke a prior opt-out, that is, opt back in to the ILHIE at any time by requesting that any of his or her ILHIE-connected providers reverse the patient's last recorded opt-out choice. The provider will send an electronic message (IHE standard) or use the provider website provided by the ILHIE to notify the ILHIE of the patient's updated preference, thus reversing the consent flag for that patient in the ILHIE's MPI.

**2. Collection of patient "opt-out" at HIE**

**a. Storage at HIE**

Preference: The ILHIE will maintain its MPI as a central registry of patient consent preferences. The ILHIE will not collect or store opt-out forms, which documentation will be collected and maintained by a patient's provider at the point of care in accordance with the provider's own policies for the collection and maintenance of patient opt-out preferences.

**b. Patient Access**

Preference: Currently, there is no electronic patient portal for the communication and receipt of a patient's opt-out consent preference at the level of the ILHIE. The ILHIE Authority will consider the feasibility of enabling this functionality, including concerns regarding the authentication of individuals.

**c. Revocation**

Preference: The ILHIE will maintain its MPI as a central registry of patient consent preferences. Initially, access to the ILHIE's MPI will be available to providers participating in the ILHIE; direct patient access to ILHIE's MPI for the management of their own consent preference may be made available at a future date. The ILHIE will not collect or store revocation of opt-out forms, which documentation will be collected and maintained by a patient's provider at the point of care in accordance with the provider's own policies for the collection and maintenance of patient opt-out preferences.

**3. Data filtering triggered by "opt-out"**

**a. At Provider EHR**

Preference: Providers who have received a patient's opt-out preference will honor this preference and ensure that notice of a patient's opt-out has been communicated to the ILHIE.

**b. At ILHIE**

Preference: The ILHIE’s MPI will be the central registry of patient opt-out preferences in Illinois. All HIEs in Illinois will use ILHIE’s MPI as the single source of information for applying patient consent preferences when handling patient data so that the opt-out choice applies to all providers. When a request comes in from a provider to the ILHIE for the purpose of obtaining an aggregated report about a particular patient, the MPI flag will be queried. If the patient has exercised an opt-out, an aggregated document will not be transmitted. Instead, consistent with the patient’s reasonable expectations, a message will be sent to the requesting provider that there is “no information available”.

**c. At Regional HIEs (RHIOs)**

Preference: The ILHIE Authority, in collaboration with the Regional HIEs, will evaluate and identify mechanisms for ensuring that patient consent preferences are accurately and consistently applied and recognized across all HIEs in Illinois.

**d. Emergency Access (“break-the-glass”)**

Preference: As the law in Illinois is unclear regarding the permitted disclosure of patient health information in the event of medical emergency without patient consent, the ILHIE Authority’s approach to overriding patient opt-out consent (“break-the-glass”) will be to seek clarification of applicable Illinois law, whether through the adoption of regulations or the enactment of laws by the Illinois General Assembly. As currently envisioned, a patient may at an emergency point of care agree to a revocation of that patient’s prior opt-out choice to enable the release by the ILHIE of that patient’s electronic medical record in response to a request from the emergency medical facility.

**4. Data filtered by “opt-out”**

**a. Global**

Preference: Data filtering as a result of a patient opt-out is global, meaning all data from all sources available through the ILHIE will be unavailable for disclosure, except as permitted by law, such as in the case of public health reporting.

**b. Per Provider**

Preference: Providers who have agreed to requests for restrictions on the disclosure of “specially protected” patient health information under Federal and State law, such as information regarding alcohol and substance abuse treatment, HIV/AIDS testing and genetic testing, will honor those requests and ensure that their EHRs, if capable, will not make such information available through the ILHIE. If a provider’s EHR is incapable of ensuring that such information will not be made available through the ILHIE, then the provider instead will require the patient to opt-out of participation in the ILHIE.

## **5. Meaningful Disclosure at Provider Point of Care**

Preference: The provider at the point of care is responsible for providing its patients with meaningful disclosure, including the distribution of a provider's Notices of Privacy Practices containing a description of the ILHIE and opt-out choice. Providers will provide patients with meaningful disclosure at the patient's first encounter with a provider who has become a participant in the ILHIE. It is anticipated that the ILHIE Authority, through its Patient Choice and Meaningful Disclosure Work Group, will facilitate the creation of template notices, sample language for Notices of Privacy Practices and other materials for distribution and use by providers in providing patients with meaningful disclosure.

### **a. Content required**

Preference: Providers will provide their patient with meaningful disclosure regarding (i) health information exchange (HIE); and (ii) a patient's right to opt-out of disclosure in an HIE. The ILHIEE Authority will have resources available on its website to assist providers in meeting their meaningful disclosure obligations.

### **b. Form of Disclosure**

Preference: Providers will provide patients (and recipients) with written notice, which may be included in the form of a provider's Notice of Privacy Practices, describing health information exchange and a patient's right to opt-out. In accordance with their own policies for meaningful disclosure regarding health information exchange and patient opt-out rights, providers may also provide patients with additional written materials concerning health information exchange and a patient's right to opt-out which directs the patient to a health information exchange website containing (i) an explanation of the purposes of the health information exchange; and (ii) audio, visual, and written instructions on how to opt-out of participation a health information exchange. Providers may also utilize written signs, posters, brochures, pamphlets, website postings, Q&As, audio-visual information and oral briefings to educate patients about health information exchange and patient opt-out rights.

### **c. Patient Acknowledgement**

Preference: Providers may require their patients to execute an acknowledgement of receipt of meaningful disclosure for inclusion in the patient's medical record in accordance with the provider's own policies for meaningful disclosure regarding health information exchange and patient opt-out rights.

## **6. Meaningful Disclosure at HIE**

### **a. Content required**

Preference: Each HIE will establish a publicly-accessible website containing (i) an explanation of the purposes of the health information exchange; and (ii) audio, visual, and

written instructions on how to opt-out of participation a health information exchange. The explanation will include the HIE's purposes and potential uses, and the fact that the HIE will disclose a patient's health information to participant in the exchange unless the patient elects to opt-out of further HIE disclosure. The instructions will include the procedures to be followed to opt-out of further disclosure by the HIE, except to the extent provided by law.

**b. Form of Disclosure**

Preference: In addition to their own website content, HIEs may develop for their own purposes and for providers additional written and electronic notices and materials concerning health information exchange and a patient's right to opt-out including signs, posters, brochures, pamphlets, website postings, Q&As and other means to educate patients about health information exchange and patient opt-out rights.